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Transforming identities through Transforming Care: how people with learning disabilities experience moving out of hospital

Accessible summary

- People with learning disabilities talked about what it was like to move out of hospital.
- People talked about how important their relationships with other people were. People wanted to feel comfortable with new members of staff so that they felt safe and happy in their new home.
- People talked about how moving out of hospital changed how they thought about themselves. When they were in hospital people sometimes thought that they were 'bad'. But after they moved, some people started to think that they were a different person. It is important for everyone to think about how they talk to people when they are in hospital, and when they have moved out.
- People can do really well living in their own home, rather than in hospital.

Abstract

Background

People with learning disabilities are moving out of hospitals as part of the Transforming Care programme, though thus far their views on how they have experienced this have not been researched.

Materials and Methods

A qualitative design was used to explore how people with learning disabilities experienced moving as part of Transforming Care. Eleven people took part in semi-structured interviews; they were supported by Key Support People (n=9) who knew them well. A social constructionist Grounded Theory approach was used in analysis.

Results and Discussion

People reported that their relationships with other people, including friends, family and staff, played a significant role in how they experienced the move. Moving was also an opportunity for people to shift their ideas about who they were as a person, and opened up a wider array of stories about their identity

Conclusions

A number of recommendations are discussed, relevant for staff working in this field to support positive transitions out of hospital.

Introduction

This paper describes research investigating how people with learning disabilities experience moving out of hospital into the community as part of the Transforming Care programme. In 2011 undercover filming exposed the abuse and mistreatment of patients at Winterbourne View, a privately-run hospital for adults with learning disabilities (BBC, 2011). The government subsequently launched a national review into how such hospitals are managed (Department of Health, 2012). These inspections revealed too many people were residing in inpatient services without enough or adequate assessment or treatment, and people often remained in hospital for longer than necessary before being discharged (Bubb, 2014). The resulting Transforming Care report (Department of Health, 2012) set out plans for service delivery whereby people with learning disabilities should live in their own homes in the

community, with individualised personalised packages of support (Department of Health, 2015). Nevertheless, figures show the number of people in hospital continues to rise: from 2255 people in 2015, to 2550 people in October 2016 (NHS England, 2016).

Deinstitutionalisation at the end of the 20th century and beyond has been the focus of empirical studies internationally, indicating overall improved quality of life in smaller community homes than in large-scale institutionalised hospitals (Chowdhury & Benson, 2011; Kozma, Mansell & Beadle-Brown, 2009). However a systematic review of the literature (Head, 2017) revealed that there is limited research into how moving out of hospital is experienced from the perspective of people with learning disabilities themselves. Research pre-Transforming Care indicated that moving out of hospital could be a time of significant challenge and distress, especially when there was a lack of certainty about the process, or when there was a lack of consistency in staff teams (Hubert & Hollins, 2010; Johnson, 1998; Owen et al, 2007). This is significant, as a 'revolving door' pattern of admission has been noted (Royal College of Nursing, 2016) whereby placements breakdown and readmission occurs. This can lead to further disruption, uncertainty and distress for the person with learning disabilities, and significant costs for social services and the NHS.

Research on the impact of moving under the Transforming Care programme is extremely limited, with just one case study which focused on one man's move from a long-stay hospital (Leaning & Adderley, 2015). Some of the challenges and opportunities that this transition posed for him and those around him were highlighted. Given that Transforming Care has a responsibility to move those with complex needs into permanent and successful homes in the community, there is a clear need for further empirical research into peoples' experiences of moving. The aim of the present study was therefore to explore how people with learning disabilities experienced the process of moving as part of Transforming Care.

Method

Ethics

The project was given full NHS ethical approval (IRAS no: 200695). Particular care was taken to assess and monitor consent over time (Cameron & Murphy, 2007), as well as maintain confidentiality and participant wellbeing.

Participants

11 participants were recruited through the local multidisciplinary Transforming Care team. Participants were identified by members of the team, and invited to approach the main researcher if they were interested in taking part. Participants had moved to the community between four months to two years before interviews; and had waited between four to 18 months for the proposed move to take place. All participants were diagnosed with a learning disability and considered to be in the mild to moderate range. All participants had also received a diagnosis of a mental health problem and/or behaviour which challenged. Time spent in hospital prior to discharge under Transforming Care ranged from four years to over 40 years. Further participant information can be found in the original doctoral research report (Head, 2017). Participants were invited to create their own pseudonyms to aid a sense of ownership over the research. Nine additional people participated as Key Support Persons (see Procedure below), including parents, a social worker, a support worker, nurse and home manager.

Procedure

An individual semi-structured interview was conducted with each participant by the main researcher, who was not known to the participants prior to the study. The interview schedule was personalised to participants' specific communication needs, for example through the use of photos to aid responses (Finlay & Lyons, 2001; Rodgers, 1999). Participants were asked about their experiences before, during and after moving. See box 1 for sample interview questions.

All participants also took part in a second interview. A dyadic interview technique was used (Caldwell, 2013), whereby the participants each identified a non-disabled Key Support Person (KSP) who knew them well to support them with the interview. "Internalised other" interviewing was used to interview the KSP. This is a technique adapted from Karl Tomm and systemic therapy (cited in Haydon-Laurelut & Wilson, 2011) for use in learning disabilities family therapy (Baum, 2007). It invites the non-disabled party to step into the shoes of the person with disabilities, and speak from their perspective in the first person. It has been proposed as a powerful tool to bring all voices into the room (Haydon-Laurelut & Wilson, 2011). This technique was used for the second interviews, such that the KSP was interviewed 'as if' they were the person who had moved (Head et al, 2017, in preparation). The potential power imbalance in such a dyad was considered, and in an effort to redress this balance, participants were invited to listen to, amend and build on the responses of the KSP. Interviews at both stages lasted between 30 and 90 minutes.

Data Analysis

Data was analysed using Grounded Theory methods drawn from the social constructionist approach of Charmaz (2014). This involved a process of constant comparison of evolving concepts and categories to new and existing data, such that the resulting model remained grounded in the participants' data. Theoretical sampling is a technique used within Grounded Theory to identify specific participants whose experiences could help strengthen an aspect of the evolving model which is under-developed (Charmaz, 2014). This was used in the present study to identify a participant who had returned to hospital after a placement broke down, in order to further explore the experiences of waiting to move. A research diary, memo writing, peer support and supervision were used self-reflexively throughout the analysis. Memos were used particularly to reflect on and aid the analysis of differing accounts – for example, to link how participants spoke about their experiences in relation to the length or complexity of their transition pathway, and factor these differences into the evolving model.

Results and Discussion

Overall, the research demonstrated that participants went through a significant change process when moving from hospital to the community, whereby they needed to adapt to a different kind of life after their move. They navigated shifting beliefs about their identity, which were also shaped by how other people around them perceived them. Two key aspects of the results will be discussed below, namely *being in relationships with others* and *changing ideas about who I am*.

Being in relationships with others

The participants in this study reported just how significant others were in how they experienced their lives during and after moving. It was notable that a significant part of the

moving experiences for many participants was that of sadness linked to the loss of important relationships, with staff or other clients:

Larry: My friend Jerry... he lives in Ireland, I don't know what part. I haven't heard from him since I left. And, you know, I'd like to hear from him one of these days but I don't think I ever will. I miss Ola and all. He was a staff there. He was a very good bloke he was, to me, to everybody.

Jason: I miss all the staff. I miss [named nurse].

Moving often meant the loss of contact with staff with whom they had developed trusting relationships, where they felt known and therefore safe:

Interviewer: What was it like moving that often [from multiple hospital placements prior to Transforming Care]?

Social worker, Clive's KSP, speaking as Clive: I hated it. Cos I was scared. Because I was worried people wouldn't know how to take care of me. I was worried they wouldn't put my thickener in my food. And I would become ill.

Previous research has also noted that frequent dissolutions of close relationships tend to characterise the lives of people with learning disabilities (Horn & Moss, 2014). Staff in learning disability services have been postulated to act as attachment figures for service users, by acting as a secure base and thus modulating peoples' stress and anxiety (De Schipper & Schuengel, 2010; Watt & Brittle, 2008). The ending of such relationships can therefore understandably be a significant loss to people when they move out of hospital, particularly when they have lived there for a long time. However, how such loss impacts on people with learning disabilities (for example, an increase in distress or behaviours which could be seen as challenging) can often be overlooked (Johnson, 1998).

For many participants, loss of established relationships was countered by the gaining of new - or re-establishment of existing - relationships. Many participants spoke of having lived far from their families in hospital, sometimes out of county, which made visiting difficult:

Darling: I got very depressed at times [in previous placements], and very upset. Because, I weren't seeing my family enough, and I was missing 'em.

Interviewer: Did you want to live in X town?

Fred: Yes I did. Cos it was nearer to, it was nearer to me Mum. Bit nearer.

Many participants had the opportunity to meet and work with their new staff teams as part of their transition, either through visiting their new placement or staff from the new community setting working shifts in the hospital prior to the move. This was reported to be valuable in aiding a smoother relocation process:

Pamela: When I found out I was moving, it was a bit scary. The staff where I was living [in previous placement] brought me here. And I didn't want them to leave. But I met [current Support Worker] and she was really nice. I met her in [previous placement]. I knew her, and that made me feel a bit easier because I knew

somebody already here. [Before I moved] the new staff came to the hospital I was in, they came and we went shopping. And got to know 'em, they stayed with me from 10 o'clock until six o'clock at night.

Once settled into their new residence, participants continued to develop social relationships, although for the vast majority this was characterised by contact with only those in the home, staff or family. This replicates previous findings showing people with learning disabilities rarely formed significant relationships in their new communities after relocating from hospital (Bigby, 2008). Meaningful integration into the community appears to remain a significant challenge for people with learning disabilities. Some spoke of finding some connection to wider social networks, such as church or with neighbours. It felt important to some participants to feel known in their local community (for example, when they went to buy a paper) as this fostered a sense of belonging.

It was notable that many participants spoke about feeling like their support staff were akin to a friendship group or family:

Pamela: "I don't call the staff 'staff', I call them family. They're my family."

One participant, TJ, highlighted how important it was to find support staff who were a similar age and had similar interests to him, indicating he aimed to find staff who could function as a peer group as much as a professional team. Another participant, Elvis, referred to his staff team as 'friends' rather than support workers.

How participants felt they were seen in the eyes of those important to them, including family members and staff, seemed to have a large influence over how they made sense of themselves as no longer being 'patients' (that is to say, people in need of hospital treatment). At the time of moving out, it seemed to be important to be seen as ready to move:

Interviewer what did it mean to you, that other people thought you were ready to move?

Elvis' Mum, speaking as Elvis: the world.

Being treated differently seemed to also play a significant role in changing the ways that participants saw themselves. This indicated a recursive relationship between identity and action, whereby the actions of others influenced the self-image held by participants:

Pamela: We were treated like patients.

Interviewer: What does that mean to you, to be a patient?

Pamela: Horrible... it made me feel that I couldn't do anything for myself.

Interviewer: What do you feel like now?

Pamela: Really good, I can do things myself now. They don't treat me like a little kid.

Having moved, the appreciation that participants felt from others about their progress seemed to also reinforce this belief in a more positive self-image:

TJ: Every time we was in a meeting [Mum] goes “oh I’m so proud of you TJ.” It was really nice to hear, and made me want to carry on doing what I’m doing so. Really commit to it.

The interactive role that other people and oneself seemed to play in modifying participants meaning-making about their identity will be further explored in the following section.

Changing ideas about who I am

In hospital, participants reported at times having felt controlled and restricted in their environment; and at times, they reported instances of threat or abuse at the hands of staff.

Darling: [In previous hospital placement] I just weren’t coping. I was just crying, depressed, sleeping. And, just weren’t coping.

Interviewer: What was making you cry there?

Darling: I just didn’t like it, the staff were rude. The staff weren’t very nice to me. They used to hurt me when they were showering me. They wouldn’t let me shower on my own. And I told them I could do it myself.

Fred: When I was in [ward name] I got, I got dragged from the hallway right down to the kitchen. By a member of staff. I was totally upset.

At various points in hospital, many participants had used behaviours which could be labelled as challenging, which served the role of communicating their needs or their distress. When talking about their time in hospital, many participants described themselves in ways that indicated these behaviours had come to mask other aspects of their identity. It seemed that both they, and those around them, focused predominantly on the aspects of their identity which aligned with a ‘behaviour which challenges’ story. They spoke of seeing themselves as ‘being bad’, ‘naughty’, or solely a ‘risk case’ whose identity beyond their behaviours had diminished:

Interviewer: What sort of person were you when you lived in the unit?

Larry: Terrible

Interviewer: Why was that?

Larry: Naughty man.

The language used by others in these settings seemed to play a significant role in how participants made sense of their behaviour and their identities in hospital. In the quotation below, the way that Oliver discusses ‘being bad’ as a person, rather than his behaviour being seen as ‘bad’, indicated that participants often internalised a sense of a negative and restricted identity:

Interviewer: What advice would you give another person if they were going into hospital, like you?

Oliver: Behave yourself. And do the treatment. And you’ll get out. If you’re good. If you’re bad – forget it.

Gillman, Swaine and Heyman (1997) reflected on the “tyranny of professional discourse” (p.675), stating that problems can arise when ‘life’ stories become solely ‘case’ stories. In

these instances, the identity of the person can be lost, whereas the only information that gets retained is that which is useful for professionals (e.g. risk, medical). This seemed to have happened in hospital for many of the participants in the present study. Dallos and Draper suggest that “at any given moment and in different contexts, one aspect of our identity may dominate another” (p.97, Dallos & Draper, 2010). For participants in this study, it seemed that in hospital, one side of their identity (namely, aspects which were seen as challenging) could override other characteristics. This was highlighted neatly by Larry’s KSP (speaking as Larry) when she said “I think who I was as a person got forgotten, it was this behaviour that was the main factor that, that drove everything that happened in my life.”

However, on moving out of hospital, participants spoke in new ways about their sense of identity. For some, this was back to an old way of being, that perhaps had not been permitted or given space to exist in hospital:

Dave’s Dad, speaking as Dave: I’m back to the person I used to be. I think I’ve discovered how to be mischievous again. In a way that I was never mischievous at [hospital]. The opportunity to be mischievous wasn’t there.

For others, it was a transition to someone ‘more mature’, to a ‘good person’, or to an adult role:

Pamela: I used have a bow in my hair. When I first came here.

Interviewer: And why don’t you wear it anymore?

Pamela: Because I don’t want to, I’m not a girl. I’m not a child.

Nevertheless, sometimes the stories that participants had internalised about themselves in hospital were hard to shift in the community, leaving some with a sense of threat that they could be re-hospitalised for ‘being bad’:

Fred: If anything goes wrong, if you step out of line, you’re probably going back to [forensic hospital] and they throw the key away.

This is not an unrealistic belief, as the Transforming Care agenda proposes that time-limited hospital admissions may be appropriate for assessment and treatment of mental health and behavioural difficulties (Department of Health, 2012). This belief could however be problematic if leading to a constant feeling of anxiety that their community placement could break down at any minute. The findings indicated that the stories people came to believe about themselves in hospital could have a very long-lasting hold on them.

The results from the present study align themselves with previous theoretical understanding of how identities are developed through language and the process of interacting with other people (Giddens, 1989, cited in Svifris, 2017). Previous research on people with learning disabilities’ identity transformation as a result of moving home has been explored by Jahoda and Markova (2004). They noted in their study that peoples’ sense of self can be understood as a complex interaction of treatment by others and self- awareness, in comparing oneself to an internalised version of a ‘typical’ person (Jahoda & Markova, 2004).

The findings indicated that in their new homes, people were given opportunities to widen out the stories they and others held about them, rather than focus on a problem-saturated narrative (McParland, 2015). Guidance on the use of Positive Behavioural Support (PBS) to work with behaviours which challenge (NICE, 2015) similarly emphasises proactive improvements to the person's environment and daily life as a way of situating such behaviours within environmental contexts rather than relying on purely internalised explanations (Banks et al, 2007). This wider understanding of behaviours was spoken about by participants.:

Elvis' Dad, speaking as Elvis: Obviously I have my bad days. But when people understand my bad days...and they know how to treat me well when I'm having a bad day, I find it much easier to come out of that bad place. Than if I'm just ignored, or shut in a room.

Alongside participants' changing ideas about who they were, they were also able to learn new skills and ways of living that fitted more with these new identities as 'person in the community' rather than 'patient'. Participants talked of having more choice in the community-though having more control was a process of adaptation rather than an overnight change – and of facing problems in more constructive ways:

Interviewer: So do you face any problems now?

Pamela: No. I talk about them now.

Interviewer: Is that different?

Pamela: Yeah, because I used to keep them in me.

Interviewer: And what happened then?

Pamela: I got depressed, I got upset. I started hurting myself. But now I haven't done it for ages.

Conclusions

Findings from the study indicate that moving out of hospital as part of Transforming Care was a complex process of adjustment and adaptation, which lasted far beyond the day of the move. The findings indicate that being in hospital can have a profound influence on how people with learning disabilities see themselves; these narratives can develop and be maintained in hospital settings, and often seem to have an enduring power over peoples' sense of identity.

For the participants in the present study, moving was an opportunity to extend and elaborate this sense of identity from something narrow or problem-focussed, to becoming someone who had a wider array of meaning making about who they were. Other people around the person who moved, including support staff and families, played a significant role in influencing how they experienced their move and how they shifted their identities.

While people across England are moving out of hospital, the progress has been slow (Bubb, 2014). A large number of people remain in hospital, and/or are readmitted after discharge when a community placement breaks down (Bubb, 2014). Nevertheless, it is clear from the

present research that when given the opportunity with the right package of support in place, people with complex needs and learning disabilities can successfully transition to community settings. People drew on a range of resources and abilities to go through the challenges of moving out, to discover new skills and new ideas about who they were and to move forwards in their lives after hospital.

Implications

This study highlights a number of important areas which can support the successful transition to community living, and reduce the chance of placement breakdown:

- Where hospital admissions are deemed necessary for reasons of behaviour which challenges (Department of Health, 2012), a broad formulation of the unmet needs leading to the behaviours should be developed and shared promptly. In this way, those involved in the person's care may be able to understand the behaviour more in context, and adapt their language so that the person is less likely to internalise a sense of a negative identity associated with the behaviour.
- Staff from the new home in the community should work with the person in the hospital setting before they move, to help with developing new relationships.
- The emotional impact of the move, including managing the loss of close relationships, should be taken into account by staff teams throughout the moving process, as well as longer term after the move. People should be given opportunities to discuss their emotions, which might be complex and contradictory.
- It may be beneficial for staff teams in the new placement to reflect on the person's emotional journey through the use of 'internalised other' reflective practice. A reflective exercise could be used whereby staff members are asked to step into the shoes of the person who is moving and talk about how they feel (Haydon-Laurelut & Wilson, 2011). By inviting staff to think through what the person transitioning may be feeling and thinking from a first person perspective, a broader awareness of the challenges of the move could be appreciated.
- It may be beneficial for staff in the new residence to be mindful of ways in which they can support people to maintain friendships after the move; for example through the use of Skype calls, social media or arranging visits.
- The use of PBS approaches can be valuable in contextualising behaviours, rather than seeing them as an intrinsic 'badness' within the person. There is still the need for thoughtfulness over language, as identities can be seen to be constructed in conversations (Hedges, 2005). Staff should endeavour to use language which situates the behaviour outside of the person – for example rather than saying "you are challenging", explaining: 'you did something challenging because we did not support you right'.
- Staff should be mindful of emphasising strengths and abilities to move away from dominant discourses of 'disability' (Webb-Peploe & Fredman, 2012).

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